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Committee on Government Reform Hearing-*Stalking a Furtive Killer: A Review of the Federal Government's Efforts to Combat Hepatitis C.*

HEPATITIS C TESTIMONY

DECEMBER 14, 2004.

I was 5 years old when my father was diagnosed with hepatitis C. At the time I really didn't understand what this meant but I could tell that my mother seemed to be very concerned and I sensed that something was gravely wrong. By the time I was in 4th grade my father's physician started him on a course of interferon in hopes of riding him of the virus. My dad had to give himself painful injections of the drug several times a day and the drug caused him to become seriously ill. I can remember vividly my dad lying on the couch with a fever of 102 and shivering as if he had a bad case of the flu. During the time my dad was on interferon he became depressed and seemed like a completely different person to me. The smallest event could cause my dad to literally go ballistic almost like he had changed into the Incredible Hulk. Our family experienced a great deal of stress and turmoil throughout the interferon treatment and we were all thankful to reach its end. Although he went through nearly six months of sheer torture, the interferon had no effect on his hepatitis C virus. Needless to say, we were all heart broken at the failure of the treatment.

Several years later my dad became a patient of the Halt C study and was started on a course Pegylated interferon with Ribavirin at the National Institute of Health. Before beginning the treatment he was given a liver biopsy and they discovered that he

had cirrhosis of the liver. He finished the less painful course of the interferon treatment only to find out once again that it had no effect on the virus. My dad felt as if he had failed the treatment but in truth the treatment failed him.

In the fall of 2003 I was in my advanced marketing class and we were deciding what we should focus on as a public relations project for the school year. I introduced the idea of doing a project on hepatitis C because it was real life for me and our Robinson DECA chapter has always dealt with serious issues that impact the lives of people who are greatly loved. We discovered that a bill had been introduced in May of 2003 that would allot \$90 million dollars for research and education on the hepatitis C virus. As you know Congressman Davis, our DECA chapter takes on tough issues. We've worked on the Ricky Ray Hemophilia Relief Fund Act, The Good Samaritan Law which protects users of automative difibulators, and most recently the Dirty Diamond Act. I learned that Senator Kay Bailey Hutchison had introduced bill S.1143, so I immediately contacted her office to see what we could do to help. I was then put into contact with Sharon Phillips, president of the Hepatitis C Advocacy Network based in Texas and she was instantly by our side.

She and Lorren Sandt of the Hepatitis C Caring Ambassadors Program flew to Virginia and came to educate our advanced marketing class. After Lorren and Sharon's powerful visit where we learned that 4 million Americans were infected with hepatitis C and 10,000 Americans die each year of the virus, our chapter unanimously decided that hepatitis C would be our public relations project.

Since October of 2003, nearly 500 marketing students from Robinson Secondary School have been working on Capitol Hill, visiting congressional offices, and persuading

health LA's to encourage their members to co-sign The Wilson/Towns Hepatitis C Epidemic Control and Prevention Act HR3539. We have letters, phone calls and e-mails of encouragement from hundreds of hepatitis C patients across the country.

I have a story to tell you concerning some of the frustrations that come along with explaining hepatitis C to the public. A year ago this month 80 Robinson marketing students went to New York City for our annual marketing field study. We planned a side trip at 5:00 A.M. to visit Rockefeller Center and be a part of the studio audience of the Today Show. Of course being good marketing students we couldn't miss the opportunity to promote our 5 Fruits and Vegetables a Day campaign, our Child Safety Civic Consciousness project, and of course the hepatitis C public relations campaign. Each student was manned with a poster, except, only five posters out of 80 were allowed into the Today Show fenced in area. We were told, "The Today Show has a family audience and the sexually oriented hepatitis C thing would not be appropriate for the audience." Security literally threw away our posters because they thought hepatitis C is a sexually transmitted, dirty disease.

Chairman Davis, when we began this project a year ago, no one wanted to talk about hepatitis C. Even a Congressional Aid told one of our students that the number of recorded deaths from hepatitis C in their state was not enough to pass a bill. Just one death is too many. The American people have the right to know about this silent epidemic. Our government needs to be proactive so we are not caught off guard like we were with the HIV/AIDS virus in the 1980's. In this audience today our representatives from the Hemophiliac community know all too well about viruses that are spread through our blood supply. Our DECA chapter spent seven years working on the Ricky Ray bill

with hemophiliacs like Ellis Sulser and Dana Kuhn, who are currently co-infected with hepatitis C and HIV. Will our generation have a chance to survive hepatitis C? The answer is yes Chairman Davis, if we can stimulate research and education during the 109th session of Congress.

Chairman Davis, as I close my speech, I would like to say, I know you are here representing your constituents and we believe you care about Americans like my father, Gene Stein. If we don't provide funding for research and education for hepatitis C, it will impact each and every one of our lives. As they say we can pay now or we can pay dearly 10 years from now when it may be too late for millions of Americans and dads just like mine. Thank you for this opportunity and please expect to see a DECA member in your office looking for support after the bill has been reintroduced.

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Bio for Erika Stein-

Erika Stein is a 4th year member of Robinson Secondary School DECA, in Fairfax, Virginia. DECA is an association of marketing students that consists of over 180,000 members internationally. Erika is currently a senior and has been active in varsity as well as competitive cheerleading; she has earned several academic awards, and will be majoring in advertising at the University of Tennessee at Knoxville. Erika has held several offices as a member of DECA. Currently she is the Virginia DECA Executive Vice President and is Project Director for her DECA chapter's hepatitis C Public Relations campaign.

Erika is a vocal advocate for hepatitis C as her father is a victim. As a junior she involved her 300 member DECA chapter last year in promoting the Wilson/Towns Hepatitis C Epidemic Control and Prevention Act. The students have been actively lobbying both houses of congress for the past two years and are very pleased that Congressman Tom Davis has agreed to the hearing today.

